

Executive Summary

Background

Genetics affects us throughout our lifespan. In Hawai'i, three to five infants out of every 100 births will have a significant birth defect. The majority of those birth defects have a genetic origin. One study found that approximately 30% of all pediatric hospital admissions are for children with genetic conditions¹. However, genetic diseases are not found only in childhood. Current research reveals a genetic basis for most common chronic adult diseases such as diabetes, cardiovascular disease, and cancer. Many pharmaceutical companies are studying how to tailor drug treatments based on a person's genetic make-up to optimize results and minimize side effects. In the near future, genetic screening, testing and information will be integrated into routine healthcare.

Because of the increasing use of genetic advances with a host of ethical, legal, and social issues surrounding the knowledge and use of genetic technology, it was clear that a revised State Genetics Plan was needed. The initial State Genetics Plan was developed in 1994 using information from a genetics needs assessment of Department of Health programs and genetic service providers² that had been completed the prior year. The plan guided the activities of the Department of Health Genetics Program over the past decade. It is time to revisit the needs of our community and develop a new plan to address the impact of new genetic technologies on the residents of Hawai'i.

Over the past two years, the Hawai'i Genetics Program has conducted surveys, interviews and focus groups to assess the community's attitudes, knowledge, and needs regarding public health genetics. This document presents the key findings and recommendations from the needs assessments.

Hawai'i Department of Health Genetics Program

The Hawai'i Department of Health Genetics Program (Genetics Program) works within a framework developed by the Institute of Medicine's (IOM) 1998 report, "The Future of Public Health"³. The IOM report established three core functions for public health programs: Assessment, Policy Development, and Assurance. The Genetics Program also maintains the fundamental principles of being family centered, community-based, and culturally competent when developing policies, information and activities.

The mission of the Genetics Program is to:

- Provide leadership in public health genetics;
- Develop and maintain ongoing communication with professional and lay communities;
- Promote genetic awareness through education;
- Assess and improve public health genetics programs;
- Integrate genetics into public health programs.
- Assure access to quality genetic services; and
- Develop policies to improve genetic services and protect the public.

Use of this document

Since its inception, the Department of Health Genetics Program has made use of genetics needs assessments and a State Genetics Plan to direct the activities of the program. However, this document is also directed towards anyone who may develop genetics activities or provide genetics services in Hawai'i. We encourage genetics professionals, health care providers, public health professionals, third party payers, state agency staff, legislators, educators, health care advocates, and consumers to use this updated version of the Genetics Needs Assessment and revised State Genetics Plan.

Assessment Activities

Needs assessments were conducted on key groups as identified by the Genetics Program and State Genetics Advisory Committee. The methods for needs assessment are presented in Table 1.

Table 1: Method of Survey for Identified Key Group

Group Surveyed	Survey Method
Physicians (Obstetricians, Pediatricians, Family Practitioners, Internists)	Mail survey
Family Practitioners and Internists	Telephone interview
Public Health Administrators	Mail survey
Public Health Nurses	Mail survey
Consumers	Focus groups
Genetic Service Providers	Key Informant interview

The needs assessment activities have been conducted over the past two years. The following are the key findings and recommendations from each group.

Assessment Findings
Public Health Administrators

K E Y F I N D I N G S

Only 20.0% of the public health administrators surveyed currently offer genetics services in their programs. The majority of the respondents are not planning to incorporate genetics education or genetics services into their program activities in the next five years.

Public health administrators think that the impact of medical genetics on public health programs will not be felt until five to ten years from now.

The majority of respondents (68.0%) expressed that access to genetic information should be regulated at both the state and federal levels to maintain confidentiality of medical records.

Assessment Findings
Public Health Administrators

R E C O M M E N D A T I O N S

- Develop an email listserv and/or a newsletter to alert public health administrators to current genetic advances and issues.
- Establish training and seminars for public health administrators to increase awareness about the links between current medical genetic advances and public health programs and policy developments.
- Emphasize professional journals and seminars as more accurate and unbiased methods of education (as compared to mass media offerings).

Assessment Findings
Public Health Nurses

K E Y F I N D I N G S

Of the 51 surveyed public health nurses with clinical responsibilities (as opposed to administrative duties), nine (17.6%) reported that they do not have any clients in their caseload with a known genetic condition.

Thirty of the 51 (58.8%) clinical nurses reported having made no recommendations for genetics referrals for their patients to the primary physician in the past 12 months; 15 nurses (28.5%) made referrals for 1 to 3 patients; and one nurse (2.0%) made 10 referrals. The remainder of the nurses did not indicate whether or not they made recommendations for genetics referrals.

Nearly one-third (15/51; 29.4%) of the public health nurses who perform clinical services were not aware of a genetics referral source in their community.

Both clinical and administrative public health nurses reported that 75.0% had no continuing education in genetics within the previous twelve months, and 19.3% had 1 to 4 hours of continuing education in genetics.

The top three most desired methods for continuing education among public health nurses were short, in-service lecture sessions (27.5%); a one-day conference during the week (26.9%); and videotapes (13.5%).

Currently, 3/6 (50.0%) of the nurses with administrative duties indicated that they include genetics in the planning of their program activities, and 4/6 (67%) reported that genetics will be included in their program plans in the next five years.

All six of the respondents with administrative responsibilities anticipated that genetics will have a significant impact on their programs and program services in the next five to ten years.

Assessment Findings *Public Health Nurses*

RECOMMENDATIONS

- Develop training programs and resources to assist public health nurses in identifying possible genetic conditions and genetics referral sources.
- Institute annual or semi-annual training on current clinical genetic advances and their intersection with public health nursing.
- Develop a lunchtime seminar series on specific genetic disorders that can be integrated into clinical practice.
- Develop an e-mail listserv to publicize important genetics news and to refer nurses to appropriate channels for further information.

Assessment Findings *Primary Care Providers*

K E Y F I N D I N G S

Among physicians in the survey, the distribution of the number of patients thought to have a genetic disorder differs according to the specialty (obstetrics, pediatrics, family practice, and internal medicine). Almost 20% of the family practitioners and internists report no patients with a genetic disorder in their practice.

Over one-fourth (27.2%) of the physicians reported having no continuing education hours on any subject related to medical genetics. Most of the physicians who did not receive continuing genetics education were family practitioners (45.5%) and internists (36.0%).

Referral patterns to genetics services differ among the four medical specialty groups. Pediatricians and obstetricians were more likely to have made a referral, at 89.3% and 100% respectively, whereas only 50% of the family practitioners and 40% of the internists had ever made a referral to medical genetics services.

Of those physicians who had never made a referral to genetics services, 48.4% were aware of a potential referral source, whereas 41.9% reported having no knowledge of a genetics referral source.

Both family practitioners and internists noted conferences and self-study as the two major methods of continuing genetics education. Additionally, both indicated a preference for shorter learning sessions during their workday.

Both family practitioners and internists think that the impact of medical genetics on clinical medicine will not be felt until five to ten years from now.

Assessment Findings *Primary Care Providers*

R E C O M M E N D A T I O N S

- Establish an ongoing continuing education seminar series specifically geared towards family practitioners and internists on general topics pertaining to medical genetics.
- Develop and disseminate professional education and training materials specifying indications for referral to medical genetics services and identifying basic criteria for high quality medical care for consumers and families affected by genetic conditions.
- Create and disseminate a directory of medical genetics services in Hawai'i with targeted distribution towards family practitioners and internists.
- Continue genetics education sessions for obstetricians and pediatricians.

- Develop monthly genetics grand rounds for family practitioners and internists covering various genetic advances with an emphasis on use in current clinical practice.
- Develop lunchtime seminars to review genetic risk assessment using case studies as examples.
- Add all family practitioners and internists to genetics program mailing list.

Assessment Findings *Consumers*

KEY FINDINGS

25/40 (62.5%) participants had received no formal genetics education.

29.1% of participants received their information on genetics from the newspaper; 28.0% from the television; and 18.6% from magazines.

All of the participants wanted to learn more about genetic testing.

Over 90% of the participants rated their knowledge of Newborn Metabolic Screening (NBMS) as “none”; 87.5% said they would like to learn more about NBMS.

The preferred methods of receiving genetics education are: short lecture followed by a question and answer period, viewing a videotape, and looking though a website.

22/40 (55.0%) of the participants felt that genetics education should be offered in middle school (grades 6-8) and high school (grades 9-12).

25/40 (62.5%) felt that genetics education should be mandatory.

The majority of participants were unaware that genetic information could be used to discriminate against people trying to obtain employment or insurance.

Over 60% (23/34) of the participants thought that government should regulate access to a person’s genetic information.

30/37 (81.1%) of the respondents thought that genetic testing by employers should be restricted.

The majority of participants indicated that genetic anti-discrimination laws should apply to medical (84.2%), disability (81.6%), life (73.4%), and long-term care (79.0%) insurance at both the state and federal levels.

Assessment Findings *Consumers*

R E C O M M E N D A T I O N S

- Create a genetics curriculum and advocate for its inclusion in the local schools.
- Include discussions about ethical and social issues in genetics in the new school curriculum.
- Develop a continuing series of public lectures on issues in genetics and have the presentations available on the genetics program website.
- Develop a relationship with newspaper and television companies to encourage accurate reporting on genetics.
- Continue to enhance the state genetics program website to be a source of educational information and resources.
- Advocate for state and federal laws to protect people from genetic discrimination.
- Advocate for laws to regulate sharing of genetic information

Assessment Findings *Genetics Providers*

K E Y F I N D I N G S

The genetics providers surveyed that reside in Hawaii and are currently in practice reported each seeing or servicing an average of 24.1 patients weekly. In the laboratory setting, an average of 50-75 tests being performed weekly was reported.

Patients serviced by the genetics providers surveyed include those in the prenatal, pediatric, and adult settings. Four of the respondents reported servicing mostly prenatal patients, four reported mostly pediatric patients, and one reported both prenatal and pediatric patients as their primary population.

Eight (72.7%) of the genetics providers surveyed reported that they provide continuing education on genetics for health care providers, primarily in the form of presentations. In terms of funding for community genetics education, all reported that they either do not provide funding or are unaware of whether funding is provided by their department/organization.

Awareness of the genetic anti-discrimination laws in Hawaii was acknowledged by eight (72.7%) of those surveyed. Two (18.2%) of the providers expressed awareness of the existence of the laws, but lack of awareness of any details.

The top need for genetics cited by the genetics providers is to obtain at least one to two full time pediatric geneticist(s) in Hawaii. Other commonly expressed needs for genetics include:

- increasing collaboration and communication between the genetics professionals and centers in the State;
- increasing public knowledge and awareness of genetics;
- continuing genetics education among health care professionals;
- increasing referrals to genetics and awareness of genetics services among health care providers;
- increasing or obtaining reimbursement from insurance companies for genetic services and testing.

The genetics providers expressed the following as the most important public health genetics issues to them:

- newborn screening;
- access to genetics services, and lack of geneticist and genetics services;
- reimbursement for genetic testing and services;
- increasing genetics education and awareness.

Assessment Findings *Genetics Providers*

RECOMMENDATIONS

- Advocate for recruitment of at least one full-time clinical pediatric geneticist with expertise in metabolic disease.
- Establish effective collaboration and ongoing communication (e.g. via a listserv) among all genetics providers in the State of Hawaii.
- Provide educational opportunities and resources related to genetics, including raising awareness of genetics referral sources and referral criteria, among various health care professionals in the State of Hawaii.
- Provide educational opportunities and resources related to genetics to the public.
- Collaborate with insurance companies to increase reimbursement for genetics services.
- Incorporate genetics services into chronic disease programs, including breast, ovarian and colon cancer, diabetes, and cardiovascular disease programs.
- Continue to advocate for the implementation of tandem mass spectrometry into newborn metabolic screening in the State, and continue to provide education regarding newborn metabolic and hearing screening.